

Running head: *Families of mentally ill offenders*

## The role and experiences of family members during the rehabilitation of mentally ill offenders

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## **Abstract**

**Introduction** – Taking care of a family member with a mental illness imposes burden on various aspects of family life. This burden may be enhanced if the mentally ill individual has a criminal history. This paper aims to summarize the scientific literature dealing with the experiences, needs and burdens of families of mentally ill offenders. We aim to explore the roles that family members play in the rehabilitation of their relative and review the families' needs and burdens. Finally, we aim to investigate whether or not the family strengths are considered in the literature.

**Methods** – A literature search in line with the PRISMA statement for systematic reviews and with the recommendations for an integrative review was performed in the ISI Web of Science, PubMed, Elsevier Science Direct and ProQuest databases.

**Results** – Limited research has been conducted into the experiences, needs, and burdens of families of mentally ill offenders, with only eight studies meeting the inclusion criteria. Families of mentally ill offenders experience more stress than those of mentally ill individuals with no judicial involvement. This is due to the fact that these family members have to deal with both mental health services and judicial systems. The eight retrieved studies focus on needs and burdens, with little reference to strengths or capabilities.

**Conclusions** – The review has highlighted the need for further research into the needs and burdens of families with mentally ill offenders, with a focus on strengths rather than an exclusively problem-oriented perspective. It is important that families become more involved in the health and social care of their relatives to avoid being regarded as 'second patients'.

## **Key words**

Family, mentally ill offenders, needs, burdens, strengths

## Introduction

Worldwide there are over 10 million prisoners, a number which is still growing (Fazel and Seewald, 2012). Many offenders in general and prisoners more in particular are facing (severe) mental health problems, with prevalence rates ranging from 10% to 70% according to different studies in the United States and Europe (Sartechi, 2013; Dressing and Salize, 2009). Although the figures widely vary, e.g. due to differences in used definitions, we could conclude that the proportion of mentally ill persons in offender populations is substantial; moreover, mentally ill offenders are described as a population for which treatment services are not adequately equipped (Koenraadt and Mooij, 2007; Sartechi, 2013; Dressing and Salize, 2009). Yet, during the last decades, the support of mentally ill offenders has received increased attention, both in research as well as in clinical practice (Roskes *et al.*, 1999; Lamb and Weinberger, 1998; Adshead *et al.*, 2013). However not only mentally ill offenders themselves, but also their family members are affected by the particular situation offenders find themselves in, although research about the resources, strengths, needs, difficulties, and coping strategies of family members of mentally ill offenders is only scantily available. Moreover, it often concerns studies with small and limited samples (Tsang *et al.*, 2002; Pearson and Tsang, 2004; Nordström *et al.*, 2006).

Taking care of a relative with a mental illness imposes various challenges or “burdens” (a concept developed by Grad and Sainsbury in 1963) on families (Marsh and Johnson, 1997; Lautenschlager *et al.*, 2013). Because the concept of ‘burden’ is often used in the literature on family members of mentally ill persons (cf. Baronet, 1999; Maurin and Boyd, 1990; Fu Keung Wong *et al.*, 2012), it is also used in this paper, although we are aware of the fact that it may be perceived as potentially stigmatizing; a connotation which certainly is not intended in the scope of this paper. Families experience difficulties both objectively and subjectively; they have to deal with both the symptoms of the mental illness, caregiving responsibilities and social stigma (objective burden) and intense emotions such as grief, disbelief, anger, guilt, anxiety and shame (subjective burden) (Thompson and Doll, 1982; Fadden *et al.*, 1987; Maurin and Boyd, 1990; Loukissa, 1995; Baronet, 1999; Marsh and Johnson, 1997; Foldemo *et al.*, 2005). Most studies have focused on families experiencing difficulties, although others have shown that families can change their lives and build family resilience over time (Marsh and Johnson, 1997; Wynaden, 2007; Mokgothu *et al.*, 2015). This shows that, given time, family members can become

empowered by recognizing family strengths. These strengths have been defined as: “*the set of relationships and processes that support and protect families and family members, especially during times of adversity and change; they help to maintain the family cohesion*” (Anderson Moore *et al.*, 2002, p.1). Hence, families are now increasingly considered as a critical source of support during the rehabilitation process of their mentally ill relative and are regarded as crisis intervention specialists because they handle relapses and emergencies and protect vulnerable family members (Loukissa, 1995; Marsh and Johnson, 1997; Wynaden, 2007). However, supportive families have to overcome cycles of hope and despair and this can create greater levels of personal advocacy and assertiveness (Spaniol, 2010). Despite this, research into the participation of families in support and treatment rarely discusses the family strengths (Spaniol and Zippel, 1988; Marsh and Johnson, 1997; Tsang *et al.*, 2003; Wynaden, 2007; Ewertzon *et al.*, 2010).

Family members that are providing support to a mentally ill relative experience emotional stress, which is often enhanced if the relative is also involved in criminal activities (Marsh and Johnson, 1997; Ferriter and Huband, 2003). Families of mentally ill individuals without a criminal record face burdens such as (1) dealing with different emotions (e.g. guilt, shame, stigmatisation, denial, frustration, anxiety, and helplessness), (2) financial concerns (early retirement or having to quit their jobs) and (3) social isolation and discrimination (Marsh and Johnson, 1997; Schene *et al.*, 1998; Tsang *et al.*, 2003). Preliminary findings in a narrative review show that family members of mentally ill individuals with a criminal record face similar issues and have to deal with a variety of stressors, including court proceedings, the media, admissions to special hospitals, contact with police and judicial systems and violent behaviour from their ill relative, which creates symptom-specific, social, financial and emotional burdens. In addition to these burdens, the needs of families are affected by diminishing work, leisure and social activity (Tsang *et al.*, 2002). Families of mentally ill offenders have to participate in caring for their mentally ill relative. Although most family members feel unprepared, they continue to support their mentally ill relative during their rehabilitation process (Loukissa, 1995; Marsh and Johnson, 1997; Wynaden, 2007). Families do not see themselves as controlling and remain protective towards their relative, for example by not involving the police if the person is violent (Ferriter and Huband, 2003; Nordström *et al.*, 2006). However, a recent study about the experiences of family members of persons subjected to Electronic Monitoring indicated that family members sometimes see themselves as assistants, social workers and “controllers” of their

relative (Vanhaelmeersch and Vander Beken, 2014). When confronted by the forensic services, families actively support their relative both practically and emotionally. Yet, they sometimes feel inadequate, institutionalised and intimidated in their role, which affects their life-course, identity and well-being (Ridley *et al.*, 2014). Nonetheless, resilience is also an important factor within these families, because it allows the development of self-coping strategies in the face of stressors and difficulties (McCann *et al.*, 1996).

The aim of this article is to review the recent literature on the experiences, needs and burdens of families of mentally ill offenders. Firstly, we aim to address the role of the families during the rehabilitation of their relative. Secondly, we aim to review the families' needs and burdens and finally we aim to examine if and to what degree the retrieved literature has explored the families' strengths. We discuss the gaps in our existing knowledge and pose suggestions for future research.

## Methods

A literature search was performed applying the guidelines of the PRISMA statement for systematic reviews as the basis for reporting (Moher *et al.*, 2010). In line with the recommendations for an integrative review (Soares *et al.*, 2014; Whitemore and Knafl, 2005), the different steps of the review study are clearly described in order to underpin the reliability and validity of the results (Figure 1). The ISI Web of Science, PubMed, ProQuest and Elsevier were examined, using the following search terms to identify studies about the role of families in supporting mentally ill offenders and their experiences, perceived needs and burdens: “mentally ill/mentally ill offender/forensic” and “family/social network/caregiver/informal network”. This yielded a total of 1466 papers, 223 of which were duplicate studies. Studies were included if they contained the perspectives of families and focused on the experiences, needs and burdens of the family or the social network. Studies were excluded ( $n = 1212$ ) based on the following criteria: (1) focusing only on the perspective of mentally ill offenders or describing drug addict offenders, (2) describing children and adolescents under 18 years of age, (3) pure medical contexts, or dealing with physical diseases such as cancer, or comparing the effect of pharmaceutical products, (4) investigating community re-entry and community treatment with exclusive focus on the mentally ill offender, (5) describing specific concepts (e.g. recovery) without considering the needs and burdens of care-givers and (6) investigating family interventions and social support. The titles and abstracts were carefully and independently read and assessed by the first author of the paper and another researcher in order to guarantee the reliability of the analysis. In case of divergent opinions, both assessors discussed these differences until agreement was reached. Based on this scrutiny, 21 articles on families of mentally ill (offenders) or reviews of these studies were selected. Screening the reference lists of the selected articles revealed an additional 49 articles meeting the inclusion criteria. A total of 70 selected articles were further processed by excluding 59 papers that were not situated in a forensic context. A further three papers were excluded because they were not empirical studies. After processing, only eight studies were evaluated; these were seven scientific articles and one report (Table 1). During the study, meetings between the first author and the co-researchers (who have experience in conducting review studies) were regularly organized, in order to discuss the planning and implementation of the different research phases.

*[Insert Figure 1 approximately here]*

## **Results**

The retrieval of only eight suitable studies from our literature search demonstrated that research into the experiences, needs and burdens of families of mentally ill offenders is limited. In two of the articles, the needs and burdens of non-forensic and forensic families were compared. Two articles described findings from a secure setting and four studies described the experiences of the families. It is clear that very little research has been carried out to disclose the perspectives of the families of mentally ill offenders. Sample sizes in the articles are limited (15–23, 79 and 72 participants). Qualitative methods including in-depth interviews were used in six studies. In five articles, the mothers and other relatives of persons with schizophrenia were interviewed. All reviewed studies were conducted within a (secure) forensic psychiatric hospital or a forensic unit. The studies all involved family members, but study eight also included a limited number of friends (5%). Different terms were used to describe the family members, including carers, caregivers, parents and relatives.

*[Insert Table 1 approximately here]*

The combined results concerning roles, needs and burdens, strengths, and outcomes are summarised in Table 2.

*[Insert Table 2 approximately here]*

### ***Role of families in the rehabilitation process of the mentally ill offender***

Families of mentally ill offenders are considered primary caregivers and as the main source of care and aftercare for their relative; however they receive little or no formal training for this and many are ill-prepared to take on this responsibility (James, 1996; MacInnes and Watson, 2002). As a caregiver, one assumes responsibility for another person, which may disrupt normal life cycle activities, such as participation in social events, employment opportunities and family relationships. The performed studies indicate that family members are considerably burdened, because of the impact on their identity, life-

course, welfare and well-being. They also feel psychologically affected, defining themselves as feeling institutionalised, intimidated and inadequate by caring for a mentally ill offender. Family members may also have to provide support to mentally ill relatives living in a secure setting. Some families assume that their caring role is suspended if their relative is living in a secure setting; however, most families still provide support in these cases by visiting and acting as informants for professionals (Pearson and Tsang, 2004; Nordström *et al.*, 2006; Ridley *et al.*, 2014).

### ***Needs and burdens***

Half of the papers described that families of mentally ill offenders experience more stress and burdens than families confronted with psychiatric problems alone. The main source of this extra stress comes from confrontation with police and judicial systems. This affects family members because they are confronted with violent behaviours, dual stigmatisation and, in some cases, a disintegration of family relationships. The potential causes of increased stress in families of mentally ill offenders are shortly summarised below:

#### ***1. Violent behaviours***

Violence from mentally ill relatives and the consequent confrontations with the police, and the judicial system are considerable sources of stress for family members (McCann *et al.*, 1996). These confrontations cause feelings of disbelief and devastation, making it harder to manage and causing more stress. Some study participants reported that media coverage of their situation caused the most stress, which could make stigma a more damaging stressor than legal proceedings (Pearson and Tsang, 2004).

#### ***2. Double stigmatisation***

Families of mentally ill offenders are confronted with a double stigma, because their relatives are seen as '*mad and bad*'. This increases the emotional burden on families; desperate feelings, such as guilt, hopelessness, frustration and shame have been reported, including media contact. These often cause



further stress, which leads to self-blame and social isolation (McCann *et al.*, 1996; Nordström *et al.*, 2006). Opinions on mentally ill persons who commit offences have also been voiced by the general public, as well as the media. In a Chinese culture, where ‘*good manners*’ are seen as very important, attitudes of the neighbours are described as a major issue. Furthermore, families find it difficult to discuss their problems with friends because of the associated stigma (Pearson and Tsang, 2004; Absalom-Hornby *et al.*, 2011).

### **3. *Disintegration of the family and diminishing social contacts***

Relatives of mentally ill offenders often withdraw from group activities in response to hostile reactions from people in society. This may isolate and exclude them from social activities, although they do want to share their stories and perceive contact with family, self-help groups and police as supportive. Study participants have reported these sources of support as more helpful than contact with psychologists, social workers and psychiatrists. Despite this, most families were unaware of community-based support for their ill relatives after their release. Family members also reported little contact with mental health professionals and consequently did not feel well advised, despite that they mentioned the hope to be more involved as informal caregivers if their mentally ill relative would agree on this. This refers for example to participating in family meetings organised by the setting their relatives stay in (e.g. a forensic psychiatric hospital). Mental health professionals were perceived as unreliable when confronted, causing emotions such as anger. Yet, some positive feelings were reported by the family members, such as not being blamed or not feeling neglected; however, on the whole, family members were disappointed with the treatment and information they receive. Study participants were hopeful for an improved quality of life for their relative in the future, which was an important source of strength. Family members believed that early and suitable psychiatric treatment could prevent violent behaviours and criminal offences, signifying that family members of mentally ill offenders often want increased support from forensic services and organisations (James, 1996; MacInnes and Watson, 2002; Ferriter and Huband, 2003; Pearson and Tsang, 2004; Nordström *et al.*, 2006; Absalom-Hornby *et al.*, 2011).

#### **4. Feelings**

Families of mentally ill offenders often struggle with blame that they are responsible for the problems of their relative, which leads to guilt, anxiety and grief. Guilt is often reported, particularly by parents and partners; some believe that the outcome would have been better if they had recognised the illness earlier or had been better able to handle the situation, while others believe that they are the cause. Families often search for explanations for the disorder, which often leads to feelings of helplessness and anxiety when no answer can be found. This creates feelings of negativity between the mentally ill offender and their family and also between the family members and professionals. Consequently, maladaptive self-coping strategies may arise, characterised by the inability to discuss problems, social withdrawal and hostile reactions (James, 1996; McCann *et al.*, 1996; Ferriter and Huband, 2003; Nordström *et al.*, 2006).

#### **Family strengths**

In the face of all these problems, relatives of mentally ill offenders can still develop adaptive self-coping strategies, including contact with other families to reduce their stress and visiting their relative, encouraging feelings of forgiveness, responsibility and tolerance. All the articles mentioned adaptive coping methods, whereby five articles focus on family interventions that were reported to be empowering (McCann *et al.*, 1996; James, 1996; Ferriter and Huband, 2003; Nordström *et al.*, 2006; Absalom-Hornby *et al.*, 2011). Psychoeducational programs were the most widely discussed method of intervention; relatives disclosed a lack of information and support from professionals and a lack of knowledge regarding the services available to them. None of the questionnaires or interviews enquired about strengths; only by analysing the material could one learn about family strengths. Only one study explained that hope is an important source of strength for families (Nordström *et al.*, 2006).

## Discussion

We have reviewed the published literature from 1996 to the present and conclude that limited findings have been published regarding the families of psychiatric relatives with a forensic history, despite the substantial number of mentally ill offenders reported in the literature. Our review has shown that studies investigating the needs and burdens of families of psychiatric relatives with a forensic history often investigate small sample sizes, which compromises the relevance of the findings to the entire population. However, most of the reviewed findings were comparable and conclude that families of mentally ill offenders are confronted with raised levels of stress because of the violence, the dual stigmatisation and the disintegration of family relationships (McCann *et al.*, 1996; James, 1996; Tsang *et al.*, 2002; Ferriter and Huband, 2003; Pearson and Tsang, 2004; Absalom-Hornby *et al.*, 2011). The criminal offence makes contact with the police, lawyers and the media obligatory, which causes increased burdens. Public exposure to the situation by the media and confrontation with the judicial system have been described as particularly burdensome (Pearson and Tsang, 2004). Families often feel left alone to cope with these burdens, without help and support from friends, relatives or professionals (McCann *et al.*, 1996). Interaction with psychiatric professionals is usually reported to be inadequate. MacInnes and Watson (2002) described that professionals should be aware of the severe burdens families are confronted with so appropriate support can be provided. Studies have also indicated that families are eager to discuss their experiences, suggesting that relatives are open to receiving psychological support (Absalom-Hornby *et al.*, 2011; Ridley *et al.*, 2014). Families need the strength to make difficult decisions and this could be accomplished by developing therapeutic family interventions, such as psychoeducational programs, formal feedback sessions within mental health services and psychological support (McCann *et al.*, 1996; James, 1996; Ferriter and Huband, 2003; Pearson and Tsang, 2004; Nordström *et al.*, 2006; Absalom-Hornby *et al.*, 2011; Ridley *et al.*, 2014). Educational programs have been positively evaluated; when families receive the information they need, their self-confidence often improves. This information must be understandable and not too technical to be useful (James, 1996). Additional services that provide treatment and support are also considered important for the well-being of the patient and their family. As mentioned before, most studies included in this review discussed the inadequate contact families have with psychiatric professionals. This indicates that families would like to be more involved in health care practices and family interventions, by having a need for clear

communication between health care professionals and them (James, 1996; MacInnes and Watson, 2002; Ferriter and Huband, 2003; Pearson and Tsang, 2004; Nordström *et al.*, 2006; Absalom-Hornby *et al.*, 2011; Ridley *et al.*, 2014). However, it remains unclear whether this applies to all families.

In summary, research into the needs and burdens of families of mentally ill offenders is very limited. Investigations into family strengths are particularly scarce. This may reflect our search approach and exclusion criteria; strengths-based perspectives may have been mentioned in some of the excluded literature. Hope has been reported to be an important source of strength, along with the need for therapeutic intervention (James, 1996; Ferriter and Huband, 2003; Nordström *et al.*, 2006). Therefore further research into the organisation of interventions and the role of professionals would be useful. Additionally, the burdens and needs of relatives require further investigation in order to develop appropriate interventions (MacInnes and Watson, 2002; Tsang *et al.*, 2002; Ferriter and Huband, 2003; Absalom-Hornby *et al.*, 2011).

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Fig. 1: Flow chart of studies relative to inclusion and exclusion criteria

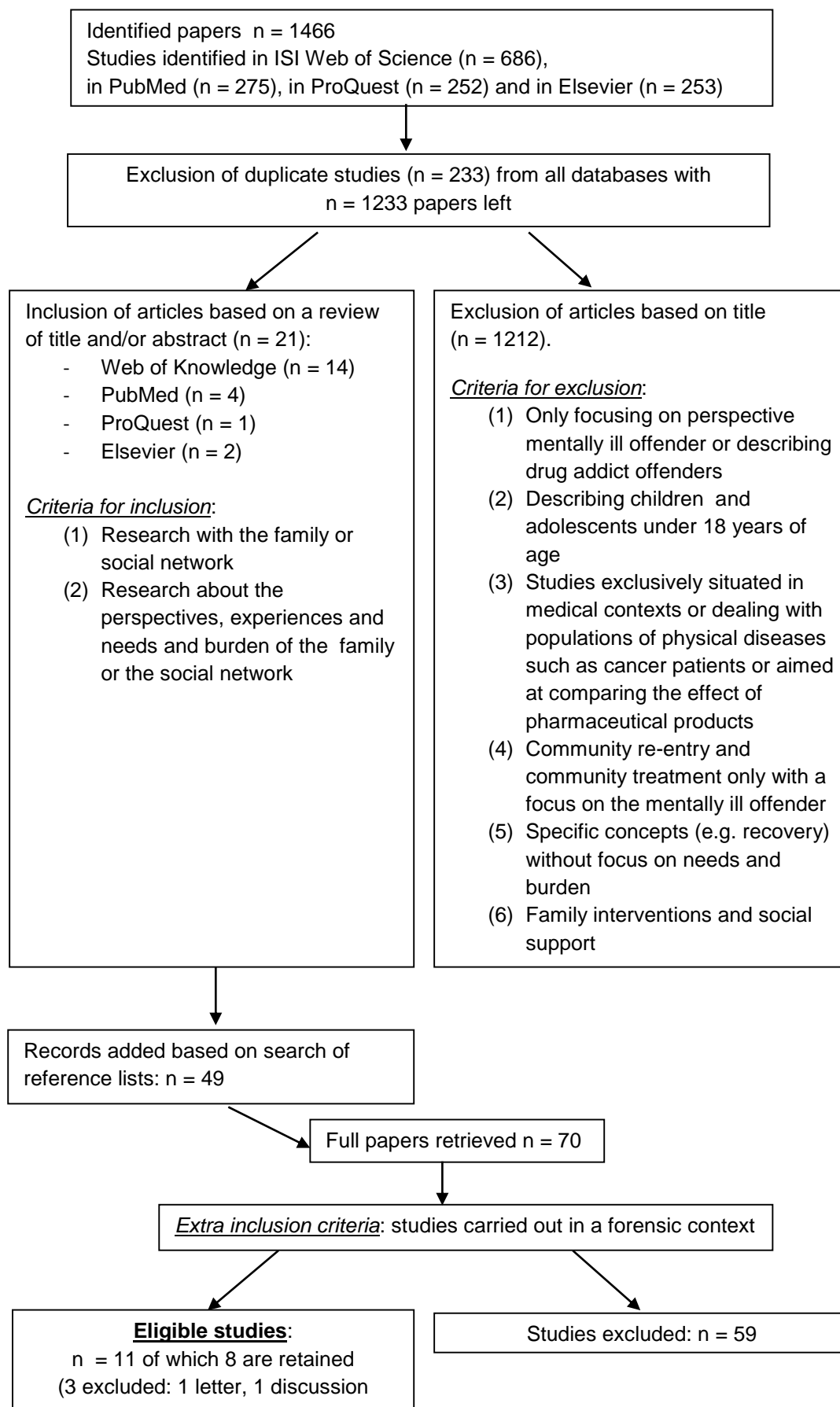




Table 1: Overview of selected articles: aim, study design, participants and instruments used in the study

Authors, date, country	Aim	Study design	Participants	Instruments used in the study
1. <b>McCann, McKeown, &amp; Porter (1996); England</b>	Evaluate the needs of relatives of patients within a forensic setting by exploring the needs and discussing the rationale upon which a more effective service for relatives could be developed.	Qualitative study with semi-structured interview at home or in a high security hospital (Ashworth Hospital).	17 participants: 14 relatives (mothers, fathers, brothers and sisters) and 3 friends of patients at Ashworth Hospital.	<p>1. RAISSE (Relative Assessment Interview, Schizophrenia in a Secure Environment, McKeown &amp; McCann, 1995) a semi-structured interview based on RAI (Relative Assessment Interview, Tarrier et al., 1988) and SNAP (Schizophrenia, Nursing Assessment Protocol, Brooker, &amp; Baguley, 1990). Concentrates on the relatives' perceptions and beliefs they experience in contact with the patient in a forensic setting.</p> <p>2. KASI (Knowledge about Schizophrenia Interview, Barrowclough et al., 1987). A semi-structured interview assessing the functional knowledge of relatives about several themes.</p>

<b>2.</b> <b>James (1996);</b> <b>Australia</b>	Describing issues that are arising from a National Mental Health Project funded programme.	Evaluations of topics that have been found to be of particular relevance to mentally ill offenders and their families.		
<b>3.</b> <b>MacInnes, &amp; Watson (2002);</b> <b>United Kingdom</b>	Examining levels of burden experienced by caregivers of people with schizophrenia, making a comparison between caregivers of forensic and non-forensic patients.	Survey design with in-depth interviews	107 caregivers were interviewed, of which 79 were forensic caregivers.	Interview schedule focused on the following thematic areas of burden: <ul style="list-style-type: none"> <li>- Specific difficulties faced by caregivers</li> <li>- Frequency that burdens were faced</li> <li>- Most worrying burdens for caregivers</li> <li>- Coping with the burdens</li> <li>- Cause of the burdens</li> </ul>
<b>4.</b> <b>Ferriter, &amp; Huband (2003);</b> <b>England</b>	Exploring the opinion of parents on the cause of the disorder, the emotional burden and the helpfulness of others when seeking support over a number of years	Qualitative study with an interview	22 parents of forensic patients selected at random. Criteria: patients diagnosed with schizophrenia and receiving treatment in a secure forensic hospital in the UK.	The participants' experience of their child's illness was determined via three methods: <ol style="list-style-type: none"> <li>1. Endorsement of items from a list of behavioural problems commonly associated with schizophrenia (Kaplan &amp; Saddock, 1989)</li> <li>2. Completion of the degree of burden scale (Thompson &amp; Doll, 1982)</li> </ol>

				3. Participation in the focused life story (Tagg, 1985)
<b>5. Pearson, &amp; Tsang (2004); China</b>	Offering relatives a voice, which would permit a greater level of understanding of professional interventions that would be both relevant and feasible.	Exploratory, qualitative study: in-depth interviews	23 participants: parents, siblings and spouses	Relative Assessment Interview (RAI) (developed by Barrowclough and Tarrier, 1992) based on the Camberwell Family Interview. Semi-structured and provides information about the problems and needs of the caregivers who are coping with patients with schizophrenia. The information is then used to guide family intervention
<b>6. Nordström, Kullgren, &amp; Dahlgren (2006); Sweden</b>	Disclosing the parents' experiences and emotional reactions about having an adult son with schizophrenia who has also committed a severe violent crime	Qualitative study with semi-structured interviews	15 participants were contacted of which 11 participated. Parents of adult sons with schizophrenia who had been recently referred to forensic psychiatric treatment	
<b>7. Absalom-Hornby, Gooding, &amp;</b>	Two main aims: 1. Determining the needs of family members with a schizophrenic relative who resided in a forensic service	Cross-sectional design using questionnaires	18 relatives of people diagnosed with schizophrenia: parents, siblings and spouses	Family Questionnaire (FQ, Quinn et al., 2003): a 48-item measure that is administered via interview

<b>Tarrier (2011); England</b>	2. Comparing the needs of family members who had a relative diagnosed with schizophrenia and who lived in a forensic service or were treated in a community mental health service			Relative's Cardinal Needs Schedule (RCNS, Barrowclough et al., 1998) is an interview questionnaire and comprises 14 sections gaining information about the relative's support, coping, relationships, hardships, and emotions in relation to the family member with schizophrenia
<b>8. Ridley, McKeown, Machin, Rosengard, Little, Briggs, Jones, &amp; Deypurkaystha (2014); Scotland REPORT CHAPTER 3</b>	Exploring carers' perspectives on the support provided by forensic mental health services and their experience of being a forensic carer	Qualitative study with a questionnaire survey and in-depth interviews	66 carers replied to the questionnaire survey (62% female, 54% parent carers). Afterwards 13 participants were interviewed and another 6 were recruited through various forensic mental health services, giving a total of 19 interviewees of which 15 were women and 12 were parent carers.	

Table 2: Overview of the findings and conclusions of the selected studies

## Role, needs, burdens and strengths of family members and outcomes of the studies

Authors, date, country	Role of family members	Needs and burdens of family member	Strengths of family members	Outcomes
1. McCann, McKeown, & Porter (1996); England	<p>- <b>Actual contact time</b> has an impact on his/her clinical management</p> <p>- <b>Family members are the first people to detect changes</b> in the patient's behaviour of their relative prior to any offence being committed and enlisted the help of psychiatric professionals</p>	<p>- <b>Life event stress</b> (the offence and surrounding aspects, long court cases and media involvement leads to long-lasting stress and to feelings of disbelief and devastation)</p> <p>- <b>Continual stress</b> (worry and anxiety about their relative his general welfare)</p> <p>- <b>Maladaptive coping methods</b> (bottling up feelings, withdrawal, feelings of revenge)</p>	<p>- <b>Adaptive coping methods</b> (attribution of the offence to the illness, ability to use others to reduce stress and visiting their relative)</p>	<p>Families need <b>more involvement in the care</b> and treatment of their relative; they need support and information about schizophrenia and its effects.</p> <p><b>Providing educational programmes</b> is positively evaluated and if organised within a group context, emotional support is generated.</p>
2. James (1996); Australia	<p>- <b>Taking care of the relative</b></p> <p>- <b>Family members are considered primary caregivers. Attempt to 'set limits'</b> often leads to threatened or physical abuse</p>	<p>- <b>Violence</b> (family as victim, anxiety and fear among the general public)</p> <p>- <b>Prejudice and stigmatisation</b> (sensationalized media) <b>and raised feelings</b> (guilt, shame,</p>	<p><b>Intervention</b> aims to <b>empower families</b> to make decisions that they have been too frightened or exhausted to make before</p> <p><b>Psychoeducational programs:</b> giving information about the mental illness, its</p>	<p><b>Providing treatment, accommodation and support</b> is an essential component in preventing recidivism and relapse and is vital for the well-being of the mentally ill offenders, their families and the community as a whole.</p>

	<ul style="list-style-type: none"> <li>- Telling their relative to move out needs to be balanced against the need not to feel rejected by the only remaining companions they possess; <b><i>maintenance of the relationship</i></b> is important</li> </ul>	<p>responsibility, forgiveness and tolerance)</p> <ul style="list-style-type: none"> <li>- <b><i>Disintegration of family relationships</i></b></li> </ul>	<p>effects and the medication as well as problem behaviours. However, relatives may be resistant to information.</p>	
<p>3. MacInnes, &amp; Watson (2002); England</p>	<ul style="list-style-type: none"> <li>- Families are seen as the <b><i>main source of care and aftercare</i></b> of mentally ill relatives</li> <li>- Families have an <b><i>unpaid and unanticipated responsibility</i></b> for their relative.</li> </ul>	<ul style="list-style-type: none"> <li>- <b><i>Violence</i></b> (experienced over a considerable period of time and also before forensic services are aware of it, can be considered the most severe burden)</li> <li>- <b><i>Annoyance</i></b> (towards services and professionals)</li> <li>- <b><i>Emotions</i></b> (hopelessness, anger and frustration)</li> <li>- <b><i>Financial burdens</i></b></li> <li>- <b><i>Burdens relating to family relationships</i></b></li> <li>- Burdens about <b><i>symptomatology</i></b> → <b><i>Need for psychoeducational approaches</i></b></li> </ul>		<p>Forensic caregivers recount a similar number of burdens to non-forensic caregivers but are likely to experience more severe difficulties and more burdens</p> <p><b><i>Services and professionals need to be aware of the severe burdens</i></b> family members are experiencing and need to be ready to support them at certain times, so that they can cope with the burdens that are placed on them.</p> <p><b><i>Professionals have to work with them as partners in care</i></b></p>

<p>4. Ferriter, &amp; Huband (2003); England</p>	<ul style="list-style-type: none"> <li>- Parents remain <b>protective</b> of their child</li> <li>- To <b>guide their approach</b>, parents <b>need information</b> about the disorder and what to expect</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Emotional burden</b> (fear, grief, shock, confusion, guilt, distress and depression)</li> <li>- <b>Financial burden</b></li> <li>- <b>Violence</b></li> <li>- <b>Stigmatization or self-blame and stress</b></li> <li>- <b>Seeking help and support:</b> family, self-help groups and police are the most helpful sources; psychologists, social workers and psychiatrist are the least helpful sources</li> <li>- <b>Need for appropriate help or advice</b></li> </ul>	<p>Need for <b>therapeutic interventions</b> (e.g. psycho-education).</p> <p>When family members receive the information they seek, their <b>self-confidence improves</b> and only a minority find the material too technical.</p>	<p>The parent group <b>experienced significant emotional stress</b>; their <b>burden was poorly alleviated by contact with professional staff</b></p>
<p>5. Pearson, &amp; Tsang (2004); China</p>	<ul style="list-style-type: none"> <li>- Some of the parents <b>will take care of the patients at home after discharge</b>, while others would not</li> <li>- <b>Sensitive</b> for the patients signs and symptoms but experience <b>problems with persuading</b> patients to seek treatment</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Media and legal proceedings</b> cause most stress (public exposure, police and courts)</li> <li>- <b>Lack of social and medical services</b> that could help families to cope</li> </ul>		<p>It should be recognized that family members of mentally ill offenders have <b>needs of their own</b>; some <b>ideas are presented to help families cope with their problems (e.g. having a few formal feedback sessions)</b></p>

	<ul style="list-style-type: none"> <li>- Family members are <b>dutiful and supportive</b></li> </ul>	<ul style="list-style-type: none"> <li>- <b>Less contact with other family members</b> (reduced social network)</li> <li>- <b>Need for information and psychoeducational programs.</b></li> <li>- <b>Emotions</b> (sad and affectionate)</li> </ul>		
<b>6. Nordström, Kullgren, &amp; Dahlgren (2006); Sweden</b>	<ul style="list-style-type: none"> <li>- <b>Searching for an explanation</b> for the onset of the mental disorder</li> <li>- <b>Initiate psychiatric contacts</b> and <b>persuade their son</b> to go to a psychiatric clinic</li> <li>- <b>Parents did not involve the law</b>; a complaint to the police was only made after a physical injury</li> <li>- <b>Supportive</b> and <b>important role</b> to play</li> </ul>	<ul style="list-style-type: none"> <li>- <b>Emotions about onset and diagnosis</b> (guilt, anxiety, fear, helplessness, sorrow, grief, and concern)</li> <li>- <b>Feelings of disrespect</b> when meeting professionals</li> <li>- <b>Violence and criminality</b></li> <li>- <b>Disappointment regarding earlier psychiatric care</b></li> </ul>	<b>Hope</b> is an important source of strength	Difficult to cope with the double burden, therefore <b>the initiative and responsibility for information, education and support of family members ought to be taken by psychiatric healthcare professionals</b>
<b>7. Absalom-Hornby, Gooding, &amp;</b>	<ul style="list-style-type: none"> <li>- Relatives have <b>reduced time</b> with the patient <b>because of the forensic limitations</b></li> </ul>	<ul style="list-style-type: none"> <li>- <b>Antisocial behaviour and negative emotions</b> are the most difficult to cope with (loss, guilt and stigma)</li> </ul>	<ul style="list-style-type: none"> <li>- No focus on strengths</li> <li>- The conclusion mentions that <b>family members found it useful to talk about their</b></li> </ul>	<b>Offer forensic families a tailored family intervention</b> , which can help families to understand the illness and to



<p>Tarrier (2011); England</p>		<ul style="list-style-type: none"> <li>- <b>Criminal offence</b> (concern and coping are heightened)</li> <li>- <b>Upset, stress and confusion</b> because of not getting the information about their relative</li> <li>- Increased <b>need for support services</b> because of severity of illness and criminal behaviour</li> </ul>	<p><b>experiences which demonstrates that they are willing to receive psychological support.</b></p>	<p>learn some coping and problem solving strategies.</p> <p>Future research: should investigate whether visiting patients ameliorates or exacerbates stress, burden and stigma for relatives and which problems families face away from the forensic service.</p>
<p>8. Ridley, McKeown, Machin, Rosengard, Little, Briggs, Jones, &amp; Deypurkaystha (2014); Scotland REPORT CHAPTER 3: Experience of being a forensic carer</p>	<ul style="list-style-type: none"> <li>- <b>Providing practical and emotional support</b></li> <li>- Within forensic services, carers have to <b>forge relationships</b> and <b>communicate with new staff</b> at every stage</li> <li>- Role has an <b>impact on life-course, identity, psyche, welfare and well-being</b></li> <li>- Forensic caring role is difficult to define because <b>they feel inadequate, institutionalised and intimidated</b></li> </ul>	<ul style="list-style-type: none"> <li>- <b>Emotional burdens</b> (traumatised, sadness, grief, frustration, anger, shame, anxiety, uninformed, left out, a shock or a relief and concern)</li> <li>- <b>Stigmatization</b> (losing friends and becoming isolated, while others felt no stigma)</li> <li>- <b>Financial burdens</b></li> </ul>	<p>Research design focuses on <b>detecting strengths and what works and why</b>, and considering how this could be extended.</p> <p>Supportive friends and family or sharing the responsibility of care helps to mitigate the stress</p> <p>Despite all the stress families could identify personal growth from the experience (e.g. more empathetic and learning to know someone better)</p>	<p><b>Stigmatization is a challenge</b> and being a family member of a mentally ill offender has an impact on all the aspects of people's lives.</p> <p>Families do not always feel supported by forensic mental health services and highlight gaps in information</p>